



Assessment of health-related quality of life of patients with inflammatory bowel diseases in Eastern Province, Saudi Arabia



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Summary Inflammatory bowel disease patients have impaired quality of life with physical, social and emotional dysfunction. This project aimed to assess the effects of socio-demographic and clinical variables on quality of life and to identify its predictors. In a cross-sectional paper-based study, 50 consecutive non-selected patients attending the teaching hospital completed a disease-specific McMaster quality of life tool. Socio-demographic and clinical data were collected from patients' records. The *t*-test and Mann–Whitney test were used to determine the probability of significant differences between quality of life domains and independent variables. Multiple linear regression was used to determine quality of life predictors. Younger and highly educated patients had higher social scores. Those with shorter disease durations had higher systemic scores. Patients in remission had higher systemic, social, bowel and overall scores. Relapse was a significant predictor of decreased systemic, social, bowel and overall scores. Long disease duration was a significant predictor of decreased systemic and overall scores. Younger age at disease onset was a significant predictor of decreased emotional score. However, high education was a significant predictor of improved social score. Relapse, long disease duration, low education and young age at disease onset were associated with low quality of life. Prospective studies should investigate how interventions addressing these predictors may lead to improved quality of life.

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Introduction

Inflammatory bowel disease (IBD) refers to chronic inflammatory diseases of the gastrointestinal tract, which include ulcerative colitis and Crohn's disease [1]. IBD commences at any time, but its highest incidence occurs between 15 and 35 years of age [2].

Researchers have addressed the presentation and initial management of Arabs with IBD in Saudi Arabia (SA) [3].

The pattern of the disease is increasing especially among young Saudi men [4,5].

IBD patients have impaired health-related quality of life (HRQOL) with physical, social and emotional dysfunction [6].

HRQOL tools provide subjective yet quantitative assessments of health perception and function in the physical, social and emotional domains, which are distinct from measures of disease activity. HRQOL tools can be used to evaluate the natural history of the disease, catalogue the needs of IBD patients, focus the direction of research and allocation of resources and assess outcome in clinical trials.

Although generic measures of HRQOL permit comparison among disease populations, they may be too imprecise to reflect impairment of function in young IBD patients or to gauge response to therapy [7]. Measuring HRQOL and identifying the variables affecting it is crucial for guiding professionals towards intervention strategies tailored to improving HRQOL.

In SA, most studies have studied the incidence of IBD and its pattern over years [8,9]. This study aimed to assess the effect of sociodemographic and clinical variables on the HRQOL of IBD patients and to identify predictors of QOL.

Materials and methods

This study was conducted in the gastroenterology outpatient clinic (OPC) and internal medicine department of a teaching hospital in Eastern Province, SA. It was a cross-sectional paper survey. Fifty consecutive non-selected patients with IBD were enrolled. Patients were recruited while receiving their treatment (January–April 2014), and their charts were retrieved to gather disease-related data. Confirmed IBD patients who were adults (teenagers and above) and were willing to participate were included. Patients with ileostomy were excluded. The researchers obtained the Arabic-translated version of the McMaster short

IBD questionnaire from McMaster University [10]. {Appendix A for English & B for Arabic version.} It is a disease-specific, validated and reliable tool for measuring HRQOL in adult patients with IBD and contains 10 questions. For each question, there are graded responses on a 7-point Likert scale ranging from one (representing the "worst" aspect) to seven (representing the "best" aspect). Total IBD questionnaire (IBDQ) scores range from 10 to 70, with higher scores reflecting better well-being. Subsequent validation of the IBDQ yielded a strong correlation with disease severity ($r = -0.5$; $p < 0.001$) and a test–retest reliability coefficient of 0.7. Significant differences also occur between active and inactive disease [10,11]. Patients' QOL data were collected through structured interviews by the study authors.

Another data collection sheet collected demographic data (age, gender, nationality, marital status, education level, smoking habits, etc.) and clinical data {disease duration, age at first diagnosis of the disease (age of onset), and disease activity (remission or relapse), method of treatment (medical or surgical), etc.}. Any surgical intervention performed to treat IBD was considered surgical treatment. However, patients under medical treatment did not receive any surgical intervention concerning IBD at all. Disease activity was classified as relapse or remission based on the charts' documentation. Physicians in the study hospital considered clinical remission as having no bowel symptoms associated with active disease, i.e., no diarrhoea or blood in stools and receiving no acute treatment.

SPSS-V20 was used for data entry and analysis. Four QOL domains (systemic, social, bowel, and emotional) and SumIBDQ (SIBDQ) were computed for data collection tool scoring. The systemic domain was composed of the sum of the responses to Q1 and Q7. The social domain was composed of the sum of the responses to Q2 and Q3. The bowel domain was composed of the sum of the responses to Q4, Q6 and Q9. The emotional domain was composed of the sum of the responses to Q5, Q8 and Q10. Finally, SIBDQ was composed of the sum of the responses to Q1–Q10. Mann–Whitney was used to test the probability of significant differences between QOL domains and the independent variables. Multiple linear regression analysis determined predictors of QOL. A p -value of ≤ 0.05 was accepted. The reliability and validity of the QOL survey was tested.

A pilot study was performed for 10 patients after receiving formal approval. The data collection sheet was revised. Patients gave prior informed consent.

Table 1 Demographic and clinical characteristics of Crohn's disease and ulcerative colitis patients attending the teaching hospital in the Eastern Province, SA (2014).

Characteristics	Crohn's disease		Ulcerative Colitis		Total		p-value
	No (31)	%	No (19)	%	No (50)	%	
Age	Mean \pm SD 27.6 \pm 11.8 Min (13) Max (61)		Mean \pm SD 33.9 \pm 15.1 Min (13) Max (70)		Mean \pm SD 29.96 \pm 13.53 Min (13) Max (70)		
13-	8	25.8	2	10.5	10	20	.130
20-	15	48.4	7	36.8	22	44	
30-	8	25.8	10	52.7	18	36	
Gender							
Male	21	67.7	8	42.1	29	58	.075
Female	10	32.3	11	57.9	21	42	
Marital status							
Married	8	25.8	10	52.6	18	36	.073
Single and ever married	23	74.2	9	47.4	32	64	
Nationality							
Saudi	30	96.8	16	84.2	46	92	.112
Non-Saudi	1	3.2	3	15.8	4	8	
Level of education							
Less than secondary school	4	12.9	7	36.8	11	22	.078
Secondary school and more	27	87.1	12	63.2	39	78	
History of smoking							
Yes	14	45.2	4	21.1	18	36	.085
No	17	54.8	15	78.9	32	64	
Place of treatment							
OPC	2	3.5	5	26.3	7	14	.049*
Inpatient	29	96.5	14	73.7	43	86	
Disease duration in years	7.90 \pm 6.68 Min (1) Max (26)		9.37 \pm 8.80 Min (1) Max (30)		8.46 \pm 7.51 Min (1) Max (30)		
Less than 5	16	51.6	9	47.4	25	50	1.000
5 and more	15	48.4	10	52.6	25	50	
Age at 1st diagnosis in years	19.65 \pm 8.90 Min (9) Max (55)		24.00 \pm 0.79 Min (2) Max (45)		21.30 \pm 9.79 Min (2) Max (55)		
Less than 15	10	32.3	3	15.8	13	26	.320
15-	21	67.7	16	84.2	37	74	
Disease activity							
Remission	14	45.2	10	52.6	24	48	.879
Relapse	17	54.8	9	47.4	26	52	
Method of treatment							
Medical	23	74.2	16	84.2	39	78	.407
Surgical	8	25.8	3	15.8	11	22	

* p value $\leq .05$.

Results

The results showed that the mean age of the IBD patients was 29.96 ± 13.53 . Forty-four percent of the patients were aged 20 to less than 30, and 58% were males. The majority were Saudis (92%), and a high percentage had secondary school education or more (78%). The majority received treatment as

inpatients (86%), and the difference was significant (.049). A high percentage received medical treatment (78%). More than fifty percent were in relapse (52%) (Table 1).

Reliability and validity of the QOL survey

Cronbach's reliability was conducted for SIBDQ and for each of the four domains to measure its

internal consistency. Cronbach's alpha values were interpreted using Richardson's suggestions [12]. Cronbach's alpha was 0.859 for SIBDQ and 0.252, 0.789, 0.491 and 0.791 for the systemic, social, bowel and emotional domains, respectively. The Cronbach alpha coefficients for the overall scale and for the social and emotional domains were considered high to very high. The Cronbach alpha coefficient for the bowel domain was average to high. The Cronbach alpha coefficient for the systemic domain was present but low.

Criterion-related validity was measured by correlating SIBDQ with each item in each of the four domains. For the systemic domain, there was significant correlation between SIBDQ and its two items (Spearman rho's R was .811 and .443, respectively). For the social domain, there was significant correlation between SIBDQ and its two items (Spearman rho's R was .836 and .419, respectively). Regarding the bowel domain, there was significant correlation between SIBDQ and its two items (Spearman rho's R was .818 and .860, respectively). For emotional functioning, there was significant correlation between SIBDQ and its three items (Spearman rho's R was .542, .515 and .594, respectively). In addition, criterion-related validity was measured by correlating SIBDQ and the four domains. There was significant correlation between SIBDQ and (systemic, social, bowel and emotional) {Spearman rho's R was .879, .879, .778 and .762, respectively}. This indicated that SIBDQ was significantly correlated with the four domains as well as with each item for each domain. Accordingly, the survey had good reliability and validity.

Table 2 illustrates the mean scores of the QOL dimensions as a function of socio-demographic and clinical characteristics. The mean systemic domain score showed a significant difference depending on disease duration; patients who had experienced the disease for less than 5 years had better QOL scores than those who had experienced it 5 years or more. Moreover, the mean systemic domain score showed a significant difference depending on disease activity. Patients in remission showed better QOL scores than those in relapse. The social domain showed a significant difference depending on patient age. Patients aged 20 years to less than 30 showed better QOL scores than patients aged 30 years or above. Moreover, the mean social domain score showed a significant difference depending on disease activity. Patients in remission showed better QOL scores than those in relapse. The bowel domain showed a significant difference depending on disease activity where patients in remission had higher QOL scores. The emotional domain did not show a significant difference with any independent variable. SIBDQ

showed a significant difference depending on disease activity where patients in remission had better QOL scores. Disease duration was nearly significant with patients who had shorter disease duration showing better QOL scores.

Table 3 presents predictors of QOL domains. The variance in the QOL score of the systemic domain due to these independent variables was 29.7% (R square = .297) and the overall regression was significant (p value = .003). Change in disease activity and duration was significantly negatively associated with change in QOL score. Relapse resulted in a decrease in QOL score of 2.186. Moreover, an increase in disease duration was associated with a decrease in QOL score of 2.109. For the social domain, the variance in the QOL score was 26.7% (R square = .267), and the overall regression was significant (p value = .006). A change in disease activity was significantly negatively associated with change in QOL score. Relapse resulted in a decrease in QOL score of 2.296. However, QOL score was statistically positively associated with education level. Having higher education was associated with an increase in QOL score of 1.728. Regarding bowel functioning, the variance in the QOL score was 32.9% (R square = .329) and the overall regression was significant (p value = .006). A change in disease activity was significantly negatively associated with a change in QOL score. Again, relapse resulted in a decrease in the QOL score of 3.486. For emotional functioning, the variance in the QOL score was 17.7% (R square = .177), and the overall regression was not significant. However, age at first diagnosis was statistically negatively associated with QOL score. Young age at onset was associated with a decrease in QOL score of 2.866. Finally, the variance in the QOL score of SIBDQ represented 28.8% (R square = .288), and the overall regression was significant (p = .009). QOL score was statistically negatively associated with disease activity and disease duration in years. Relapse resulted in a decrease in QOL score of 11.341, and long disease duration was associated with a decrease in QOL score of 8.163.

Discussion

Recently the importance of HRQOL in chronic diseases has been increasingly recognized because of its implications for patients' psychological well-being, social adjustment to the illness, and use of health resources [13]. Measuring HRQL provides important data to quantify the impact of disease on the daily life of patients [14].

Table 2 Means of QOL dimensions as a function of socio-demographic and clinical characteristics in the univariate analysis of IBD patients attending the teaching hospital in the Eastern Province, SA (2014).

Type of the disease	Systemic Mean rank	Social Mean rank	Bowel Mean rank	Emotional Mean rank	SIBDQ Mean \pm SD
Crohn's disease	25.94	27.40	24.37	23.65	44.38 \pm 11.87
Ulcerative Colitis	24.79	22.39	27.34	28.53	45.46 \pm 12.97
Age		<i>p</i> -value .029*			
20-	23.07	24.07	21.93	21.95	47.46 \pm 12.58
30-	17.36	16.14	18.75	18.72	41.95 \pm 11.45
Gender					
Male	26.07	27.21	27.62	26.66	46.18 \pm 11.63
Female	24.71	23.14	22.57	23.90	42.86 \pm 12.81
Marital Status					
Married	24.47	23.58	24.47	25.08	45.16 \pm 13.31
Single and ever married	26.08	26.58	26.08	25.73	44.12 \pm 9.99
Nationality					
Saudi	26.45	26.20	26.08	25.43	45.22 \pm 12.39
Non-Saudi	14.63	17.50	18.88	26.25	39.82 \pm 7.94
Level of education		<i>p</i> -value .046*			
Less than secondary school	23.00	17.91	19.95	27.41	41.40 \pm 13.00
Secondary school and more	26.21	27.64	27.06	24.96	45.74 \pm 11.87
History of smoking					
Yes	25.44	26.14	28.31	23.50	44.97 \pm 11.52
No	25.53	25.14	23.92	26.63	44.69 \pm 12.64
Place of treatment					
OPC	21.93	25.43	22.07	27.79	43.14 \pm 13.46
Inpatient	26.08	25.51	26.06	25.13	45.06 \pm 12.05
Disease duration in years	<i>p</i> -value .022*				<i>p</i> -value .091
Less than 5	30.20	28.22	26.96	27.96	47.69 \pm 11.80
5 and more	20.80	22.78	24.04	23.04	41.89 \pm 11.97
Age at 1st diagnosis in years					
Less than 15	22.58	24.00	23.15	29.62	44.67 \pm 13.00
15-	26.53	26.03	26.32	24.05	44.83 \pm 11.99
Disease activity	<i>p</i> -value .009*	<i>p</i> -value .006*	<i>p</i> -value .001*		<i>p</i> -value .007*
Remission	31.30	31.57	32.59	26.35	49.65 \pm 9.69
Relapse	20.56	20.33	19.46	24.78	40.64 \pm 12.61
Method of treatment					
Medical	26.32	26.38	26.38	26.23	45.65 \pm 12.25
Surgical	22.59	22.36	22.36	22.91	41.73 \pm 11.71

* *p*-value \leq .05.

Both clinicians and researchers emphasize the importance of integrating HRQOL into the assessment of chronic disease outcomes and the impact of interventions [15].

The relationship between socio-demographic and clinical factors and patient HRQOL has been investigated [16–18]. The majority of studies have indicated the importance of age, educational level [16–19] or sex [18] with regard to HRQOL in IBD processes. The present study showed that patients aged 20 years to less than 30 years and patients

with higher education levels had significantly better social QOL scores (Table 2). This could be because individuals at this age had engagement that was more social.

In addition, patients at this age are more interested in doing leisure/sport activities. Similarly, for highly educated patients, they may be more knowledgeable about the importance of participating in leisure/sport activities.

Female gender was associated with a lower HRQOL [18,20]. López et al., 2005 found that men

Table 3 Multiple linear regression model testing for the predictors of quality of life of IBD patients attending the teaching hospital in the Eastern Province, SA (2014).

Variable	β	St error	<i>T</i>	<i>p</i> -value	<i>R</i> -Square	<i>F</i>	<i>p</i>
Systemic domain					.297	4.753	.003
Relapse	−2.186	.646	−3.383	.001*			
Long disease duration	−2.109	.722	−2.182	.005*			
Level of education	.232	.762	.305	.762			
Age in years	.197	.499	.394	.696			
Social domain					.267	4.101	.006
Relapse	−2.296	.737	−3.116	.003*			
High education level	1.728	.869	1.987	.05*			
Disease duration in years	−1.045	.823	−1.269	.211			
Age in years	−.090	.569	−.159	.875			
Bowel functioning					.329	3.515	.006
Relapse	−3.486	.929	−3.753	.001*			
Level of education	2.009	1.167	1.721	.092			
Type of IBD	1.787	1.059	1.687	.099			
Disease duration in years	−.951	1.055	−.902	.372			
Age in years	−.809	.769	−1.053	.298			
Place of treatment	1.472	1.341	1.097	.279			
Emotional functioning					.177	1.892	.115
Young age of onset	−2.866	1.308	−2.191	.034*			
Type of IBD	2.152	1.185	1.817	.076			
Disease duration in years	−2.013	1.110	−1.813	.077			
Gender	−1.459	1.157	−1.260	.214			
Disease activity	−1.017	1.131	−.899	.373			
SIBDQ					.288	3.561	.009
Relapse	−11.341	3.196	−3.549	.001*			
Long disease duration	−8.163	3.135	−2.604	.013*			
Age at 1st diagnosis	−3.935	3.694	−1.065	.293			
Type of IBD	2.993	3.345	.895	.276			
Gender	−4.549	3.269	−1.391	.171			

* *p*-value $\leq .05$.

showed higher QOL scores in systemic, bowel, emotional and social symptoms and global IBDQ, and the differences were significant [14]. However, gender did not affect any QOL domain in the current study.

Other studies concluded that demographic parameters did not significantly affect IBDQ-D scores [21].

The duration of IBD, the effects of treatments, and the consequences of its complications (e.g., hospitalizations) affect the daily lives of these patients and impair their HRQOL [19]. Our results demonstrated that longer disease duration (5 years or more) was associated with significantly lower systemic QOL scores than shorter duration (less than 5 years) {Table 2}. This may be because patients experienced many symptoms, complications and consequences of therapy over time that resulted in decreased systemic QOL scores.

The clinical course of the disease is characterized by unpredictable periods of relapse and

remission in spite of conventional therapies. Many patients do not maintain a durable remission [22]. Disease activity is one of the most important factors for decreased HRQOL [23]. Patients with relapse had significantly more disease-related worries and concerns, more impaired social functioning and a reduced feeling of well-being. Patients in relapse had greater concerns, more impairment of functional status and a reduced subjective sense of well-being relative to those in clinical remission [24]. IBD patients in remission scored significantly higher QOL scores for all domains using Short Form-36 [25]. Patients in relapse had statistically lower scores than those in remission for SIBDQ and the systemic, social and bowel domains (Table 2).

Clinical variables such as type of treatment (medical treatment or surgery), therapy effectiveness, occurrence of extra intestinal symptoms, annual rate of flare-ups, their severity or the need for hospitalization have an impact on IBD patients'

HRQL [26]. Moreover, Lopez et al., 2005 [14] showed that patients undergoing surgery had lower global HRQL scores in comparison to those who received medical treatment, and the difference was significant. This contradicts the present study where there was no significant difference depending on method, place of treatment or age at first diagnosis with any QOL domain.

Crohn's disease patients were more affected by their disease in terms of HRQOL than patients with ulcerative colitis [19,27]. Other studies found that diagnosis did not influence any of the IBDQ dimensions [25,27]. In this study, the type of disease did not affect any of the QOL domains nor the SIBDQ. This finding is in line with the work of Lopez et al. (2005), where IBDQ scores were similar for both diseases [14].

Identifying the factors associated with HRQL is relevant because it may allow clinicians to modify some of them, thereby improving patients' health [14].

Predictors of HRQOL

Understanding predictors of HRQOL may facilitate interventions to improve HRQOL and overall IBD management [20].

Variables related to disease activity, such as the presence of relapse, were the most important variable for predicting HRQOL [25]. The present study showed that relapse was a significant predictor for the systemic, social and bowel domains, as well as SIBDQ. Relapse resulted in a decrease of QOL scores (Table 3).

Disease duration was a significant predictor for systemic and SIBDQ scores where longer disease duration led to a decrease of QOL scores (Table 3). This finding could be ascribed to troublesome complications of steroid therapy or experiencing more relapses over time.

This is comparable with another study as there was a significant effect for disease duration showing that those patients with short disease duration had lower HRQOL scores compared with patients with long disease duration [28]. This result was explained by the disease having a tendency to be more active in the first course or by the patient not yet receiving the most adequate treatment. Another study found no report on differences in HRQOL in patients with either short or long history of IBD.

In this study, no difference was found in HRQOL among the three groups of patients concerning disease duration: less than one year, between one and five years and more than five years [29].

Young age at onset (less than 15 years) was a significant predictor for emotional QOL (Table 3). It contributed 17.7% to the variance in emotional functioning. This could be because young patients were not able to cope with the disease, relapse or complications of therapy.

However, the literature revealed that when these lifelong illnesses are diagnosed during adolescence, a critical developmental period, the transition to adulthood could be even more turbulent. IBD patients are at risk for depression, anxiety, social isolation and altered self-image, which can all negatively affect HRQOL [30].

Prospective studies should investigate how interventions addressing these factors may lead to improved HRQOL.

Higher education level led to improvement in social QOL scores (Table 3). This is because educated patients may have more chance to read more about the disease and learn how to cope with frequent relapses. Moreover, educated patients may show higher adherence to treatment therapy. Education may improve the coping skills of patients with chronic diseases [31]. Education results in less in-patient care, fewer visits to primary care physicians, improved treatment adherence, decreased anxiety and enhanced quality of life. Patients with relatively high levels of disease-related knowledge are those with higher educational attainment and those receiving information through the internet [32].

As the assessment of disease activity was based on physicians' opinions as documented in patients' charts, this was considered a limitation of our study.

Conclusions

Relapse, long disease duration (≥ 5 years), low education and young age at disease onset (patients less than 15 years of age) may entail increased risk for decreased HRQOL.

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Competing interests

No personal, financial or any type of interest will present a conflict with respect to this work

Ethical approval

Not required.

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References

- [1] Saadah OI. Ulcerative colitis in children and adolescents from the Western Region of Saudi Arabia. *Saudi Med J* 2011;32(9):943–7.
- [2] Hendriksen C, Binder V. Social prognosis in patients with ulcerative colitis. *Br Med J* 1980;281:581–3.
- [3] Isbister WH. Inflammatory bowel disease in Saudi Arabia: presentation and initial management. *J Gastroenterol Hepatol* 1998;13(11):1119–24.
- [4] Al-Mofarreh MA, Al Mofleh IA, Al-Teimi IN, Al-Jebreen AM. Crohn's disease in Saudi outpatient population: is it still rare. *Saudi J Gastroenterol* 2009;15(2): 111–6.
- [5] Al Quorain AA, Satti MB, Al Gindan YM, Al-Hamdan A. The pattern of lower GIT disease in the eastern region of SA: a retrospective analysis of 1590 consecutive patient. *Saudi J Gastroenterol* 2000;6(1):27–32.
- [6] Martin A, Leone L, Fries W. Quality of life in inflammatory bowel disease. *Ital J Gastroenterol* 1995;27:450–4.
- [7] Irvine EJ. Quality of life – measurement in inflammatory bowel disease. *Scand J Gastroenterol Suppl* 1993;199: 36–9.
- [8] Al-Mofarreh MA, Al-Mofleh IA. Emerging inflammatory bowel disease in Saudi outpatients: a report of 693 cases. *Saudi J Gastroenterol* 2013;19(1):16.
- [9] Alamin AK, Ayoola EA, Elboshra AI, Hamaza MK, Gupta V, Ahmed MA. Ulcerative colitis in Saudi Arabia: a retrospective analysis of 33 cases treated in a regional referral hospital in Gizan. *Saudi Med Gastroenterol* 2001;7(2): 55–8.
- [10] Guyatt GH, Mitchell A, Irvine EJ, Singer J, Williams N, Goodacre R, et al. A new measure of health status for clinical trials in inflammatory bowel disease. *Gastroenterology* 1989;96:804–10.
- [11] Irvine EJ. Development and subsequent refinement of the inflammatory bowel disease questionnaire: a quality-of-life instrument for adult patients with inflammatory bowel disease. *J Pediatr Gastroenterol Nutr* 1999;28: 23–7.
- [12] Richardson R. Assessment and evaluation. Dundee, Scotland, UK: Centre for Medical Education, Ninewells Hospital and Medical School; 1988.
- [13] Casellas F, López Vivancos J, Casado A, Malagelada JR. Factors affecting health related quality of life of patients with inflammatory bowel disease. *Qual Life Res* 2002;11: 775–81.
- [14] López Blanco B, Moreno-Jiménez B, Devesa Múgica JM, Rodríguez Muñoz A. Relationship between socio-demographic and clinical variables, and health-related quality of life in patients with inflammatory bowel disease. *Rev Esp Enferm Dig* 2005;97(12):887–98.
- [15] Bernardo MJ, Balbina LB, Alfredo RM, Eva GH. The influence of personality factors on health-related quality of life of patients with inflammatory bowel disease. *J Psychosom Res* 2007;62:39–46.
- [16] Badia X, Fernandez E, Segura A. Influence of socio-demographic and health status variables on evaluation of health states in a Spanish population. *Eur J Public Health* 1995;5:87–93.
- [17] Han SW. Relationship between quality of life, symptom activity and illness perception in patients with ulcerative colitis. *Gastroenterology* 1999;116:A63.
- [18] Hjortswang H, Jarnerot G, Curman B, Sandberg-Gertzen C, Blomberg B, Almer S. The influence of demographic and disease-related factors on health-related quality of life in patients with ulcerative colitis. *Eur J Gastroenterol Hepatol* 2003;15:1011–20.
- [19] Drossman D, Leserman J, Mitchell M, Zhiming M, Zagamin E, Patrick D. Health status and health care use in persons with inflammatory bowel disease: a national sample. *Dig Dis Sci* 1991;36:1746–55.
- [20] Moradkhani A, Beckman LJ, Tabibian JH. Health-related quality of life in inflammatory bowel disease: psychosocial, clinical, socioeconomic, and demographic predictors. *J Crohn's Colitis* 2013;7:467–73.
- [21] Zahn A, Hinz U, Karner M, Ehehalt R, Stremmel W. Health-related quality of life correlates with clinical and endoscopic activity indexes but not with demographic features in patients with ulcerative colitis. *Inflamm Bowel Dis* 2006;12(11):1058–67.
- [22] Gibson PR, Weston AR, Shann A, Florin TH, Lawrance IC, Macrae FA, et al. Relationship between disease severity, quality of life and health-care resource use in a cross-section of Australian patients with Crohn's disease. *J Gastroenterol Hepatol* 2007;22:1306–12.
- [23] Larsson K, Lööf L, Rönnblom A, Nordin K. Quality of life for patients with exacerbation in inflammatory bowel disease and how they cope with disease activity. *J Psychosom Res* 2008;64:139–48.
- [24] Hjortswang H, Ström M, Almer S. Health-related quality of life in Swedish patients with ulcerative colitis. *Am J Gastroenterol* 1998;93(11):2203–11.
- [25] Yunxian Z, Weihong R, Elizabeth JI, Dagan Y. Assessing health-related quality of life in patients with inflammatory bowel disease in Zhejiang, China. *J Clin Nurs* 2010;19:79–88.
- [26] Casellas F, López Vivancos J, Badia X, Vilaseca J, Malagelada JR. Impact of surgery for Crohn's disease on health-related quality of life. *Am J Gastroenterol* 2000;95(1): 177–82.
- [27] Mussell M, Bocker U, Nagel N, Singer MV. Predictors of disease-related concerns and other aspects of health-related quality of life in outpatients with inflammatory bowel disease. *Eur J Gastroenterol Hepatol* 2004;16: 1273–80.
- [28] Jäghult S, Saboonchi F, Johansson UB, Wredling R, Kapraali M. Identifying predictors of low health-related quality of life among patients with inflammatory bowel disease: comparison between Crohn's disease and ulcerative colitis with disease duration. *J Clin Nurs* 2011;20(11–12): 1578–87.
- [29] Athanasios GP, Ioannis GV, Ioannis AM. Assessing health-related quality of life in patients with inflammatory bowel disease, in Crete, Greece. *BMC Gastroenterol* 2002; 2:1.

- [30] Karwowski CA, Keljo D, Szigethy E. Strategies to improve quality of life in adolescents with inflammatory bowel disease. *Inflamm Bowel Dis* 2009;15(11):1755–64.
- [31] Moradkhani A, Kerwin L, Dudley-Brown S, Tabibian JH. Disease specific knowledge, coping, and adherence in patients with inflammatory bowel disease. *Dig Dis Sci* 2011;56:2972–7.
- [32] Blumenstein I, McDermott E, Keegan D, Byrne K, Ellison M, Glen Doherty G, et al. Sources of information and factual knowledge in Europeans with inflammatory bowel diseases: a cross-cultural comparison between German and Irish patients. *J Crohn's Colitis* 2013;7:e331–6.

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